NIEHS
National Institute of Environmental Health Sciences

Data Sharing Strategies for Environmental Health Science Research Workshop

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NIH...Turning Discovery Into Health

Purpose and Goals of the Workshop

- Clarify the scientific needs and goals for environmental data sharing
- Identify specific challenges related to the sharing of environmental health data and phenotypic data from environmental health research
- Identify best practices and successful models of data sharing that are applicable to environmental health data sharing
- Explore the technological considerations for harmonizing phenotypic data and for merging diverse datasets

NIEHS Interest in Environmental Data Sharing

- Maximizing the NIH investments in research through secondary analyses, the merging of existing data resources, and coordination between IC missions to address common and prevalent diseases
- Capitalizing on the investment of NIEHS extramural and intramural portfolio in environmental epidemiology
- Accelerating the translation of findings from genetic and environmental interactions into clinical and public health practice

Unique Considerations for Sharing of Environmental Data

- The heterogeneity of environmental and biological measurements
- The potential to identify individuals based on the association of environmental exposures with geographical data
- The increased interest in return of individual or community-level research results from environmental research
- The regulatory implications of the use of environmental exposure and health data in developing US national research policies
- The unique concerns of vulnerable populations who are disproportionately impacted by environmental exposures.

Current NIH Policies for Data Sharing

- Funding thresholds require a data sharing plan
- Policies have been developed at NIH for genomic data sharing that may be applicable and transferrable for environmental data sharing activities
  - Scientific oversight for the secondary uses proposed for archived data
  - Controlled access to individual investigators for sensitive or potentially identifiable data
  - IRB concurrence that sharing of the data preserves the intent of the original informed consent
  - Publication embargos that protect the rights of individual researchers
  - Compliance with all applicable laws and regulations

Typical Environmental Science Data Sharing Plan

"Investigators seeking data from this study must agree:

- to be approved by a data sharing oversight committee
- not to share the data with other investigators
- not to release their results until accepted for publication in a reputable journal
- to submit all protocols for IRB approval
- to comply with all other Government guidelines for research"

Next Steps

- To broaden opportunities for data sharing, attention should be given to:
  - Developing common environmental measurement vocabularies
  - Harmonizing data collection methodologies
  - Addressing future sharing of their data in informed consent processes
  - Addressing privacy and confidentiality concerns
  - Incorporating the specific needs and stated preferences of individuals and communities into their data sharing plans
  - Articulating the expectations for return of research results, scientific publications, and other forms of dissemination into informed consent processes

Next Steps Continued

- To ensure success we must consider:
  - Specific needs for de-identification of geographically based data
  - The leveraging of existing IT knowledge and resources
  - The utilization of existing processes for data sharing
  - The identification of resources for the harmonization, storage and management of data
  - The fuller incorporation of study subjects/community members preferences to guide data sharing policies

Workshop Outcomes

- Open our eyes to opportunities for future data sharing
- Specific recommendations for environmental data sharing guidelines and the resources needed
- Identification of models of data sharing applicable to environmental data sharing
- Clarification of the technical requirements and types of data required for environmental data sharing
- Dissemination of workshop outcomes and/or publications that highlight coordination of environmental and health outcomes data and scientific needs in environmental data sharing

Thank you

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